

EPF reflects on the future of the European Health Union

June 2024

EPF welcomes the adoption of the Council Conclusions on the European Health Union on 21 June, which follow the Commission's Communication on "the European Health Union: acting together for people's health". We strongly support the Council's continued commitment to **building a European Health Union based on solidarity and timely, equitable access to high-quality healthcare for all.** We regret however that the same commitment was not reflected in the European Council's Strategic Agenda for 2024-2029. As noted in the Council Conclusions, health is a precondition for the well-functioning of our society and economy, and by extension for a secure, prosperous, and competitive Europe.

As patient representatives, we are at the heart of healthcare systems and witness first-hand the gaps in patients' access to the care they need. The COVID-19 pandemic demonstrated the absolute necessity of coordination and solidarity among EU countries to address a common threat and ensure a fair and equitable distribution of medical countermeasures. Four years later, from healthcare workforce shortages to emerging health threats and tightening health budgets, our healthcare systems are facing numerous challenges which jeopardise their ability to deliver the promise of universal healthcare coverage they were built to achieve. In this context, increased EU cooperation is our best chance to strengthen European healthcare systems' ability to deliver for patients across Europe.

Since 2020, EU institutions took important steps towards making the European Health Union a reality. We welcome the extension of the mandates of the European Medicines Agency (EMA) and European Centre for Disease Prevention and Control (ECDC) as well as the creation and ongoing establishment of the Health Emergency Response and Preparedness Authority (HERA). HERA's scope has expanded to host the Critical Medicines Alliance, which aims at finding EU-wide structural solutions to shortages of certain medicines. The adoption of the European Health Data Space (EHDS) regulation will foster cross-border healthcare and research by creating a unified digital space while granting patients access to control over their electronic health data. In addition, improved patient access to safe, effective and high-quality medicines is at the heart of ongoing debates around the revision of the EU pharmaceutical legislation.

In this context, we particularly welcome the Council's focus on:

Recognising the need for ambitious joint action across a wide range of public health challenges to support more resilient, patient-centred healthcare systems. From antimicrobial resistance to the rising prevalence of chronic diseases and climate change effects on health, many public health threats do not recognise borders. Additionally, the need to transition to more sustainable, digital, and patient-centred healthcare systems is shared across countries. However, addressing these challenges effectively requires setting joint targets and priorities, pooling resources, and supporting member states in implementing best practices and evidence-based policies. It also requires meaningful multi-stakeholder engagement to build the support and trust needed to drive concrete, transformative and cohesive action. For instance, the preparatory work for the implementation of the HTA Regulation as of January 2025 shows that investment efforts to sustain the transformative potential in healthcare systems do not necessarily meet the expectation set in



the legislative framework, due to inadequate resources allocated both at European and member states level.

- ➤ Prioritising investment in health. Recent cuts to the EU4Health programme threaten the EU's ability to strengthen the resilience of our health and care systems, despite the lessons learned from the COVID-19 pandemic. Identifying synergies and raising awareness of successful examples of use of EU funds to enable measures for public health and support healthcare reform must help make the case for member states' continued and enhanced access to relevant funding schemes. The negotiations of the next multiannual financial framework (MFF) 2028-2035 will be a moment of truth for the financial viability of the European Health Union.
- Addressing unmet patients' needs. We welcome the Council's endorsement of a broad definition of unmet needs, including needs related to patients' quality of life. In the process of identifying unmet needs, we urge EU institutions to put patients' input and involvement in the decision-making at the centre. Patients have a unique expertise and experience of their condition, which should be integrated throughout the lifecycle of medical products. A comprehensive, patient-driven database of unmet needs can help inform priority setting but should not be a substitute for systematic patient involvement in medical research.

However, we call on the EU institutions to ensure a greater focus on:

- Prioritising health literacy to empower patients and improve health outcomes. With the rise of digital health technologies and limited healthcare resources, patients are increasingly expected to take a more proactive role in managing their health. In the general population, health literacy is a precondition to improve prevention, promote early diagnosis of diseases and fight misinformation, ultimately leading to better health outcomes. Citizens' awareness of their rights and understanding of the use and benefits of data-sharing are prerequisites for a successful implementation of the EHDS at national level. We urge EU institutions to drastically step up their investment in health literacy and digital health literacy to promote patients and citizens' empowerment.
- Achieving a true single market for medical products to improve patients' access to the products they need. Unacceptable inequalities in access to medicinal products between and within EU countries remain. All stakeholders must play their part in ensuring that patients have access to the treatments they need. We urge industry to carefully consider the impacts of commercial decisions on patients and prioritise their societal responsibility. We call on member states to reduce fragmentation, expand regional cooperation initiatives, and make use of joint procurement for medicines that are less commercially attractive (e.g., breakthrough treatments or older generics). Current appeals by some member states to boost industry's competitiveness and relocate pharmaceutical production should not translate into higher out-of-pocket costs for patients but into safe and sustained access. We call for improved patients' access to cross-border healthcare when receiving care at home is not possible. It is time to view the Single Market not merely as a harmonisation exercise allowing for economic growth and prosperity, but as a cornerstone of the European Health Union that fosters access equity and accountability to patients.
- Recognising the key role of civil society organisations, and patient organisations in particular, in bridging the gap between institutions and the public. From reporting to communication and participation in policy-making processes, patient organisations play a key role along the healthcare continuum. They ensure that healthcare systems and policies meet the needs of those they are



serving: the patients. EPF's <u>manifesto</u> highlights 10 key points to support more democratic and systematic involvement of patient organisations. One important aspect to create the conditions for patient organisations to play their role is unrestricted, solid, and long-term operational funding for their day-to-day activities. We call for the institutionalisation of sustainable, inclusive, and accessible operating grants at EU and national level to ensure patient groups have the resources and stability they need to fulfil their public health mission.

Although much remains to be done, we welcome the Belgian Presidency's commitment to strengthening EU action on health and outlining a path forward. We look forward to continuing to work with the EU institutions towards a patient-centred European Health Union that delivers for all patients across Europe.

ABOUT EPF

EPF is an umbrella organisation of patient organisations across Europe and across disease areas. Our 79 members include disease-specific patient groups active at EU level and national coalitions of patients representing 19 countries and an estimated 150 million patients across Europe. www.eu-patient.eu

For all media inquiries please contact EPF Communication Manager Flavia Topan at flavia.topan@eu-patient.eu



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